FUNDING HOPE

Part of the mission of AA&MDSIF is to support medical research to find effective treatments and cures for bone marrow failure diseases, specifically aplastic anemia, myelodysplastic syndromes, and paroxysmal nocturnal hemoglobinuria. We do by awarding about $200,000 each year to new and experienced researchers. Since 1983, many young doctors have been encouraged to pursue their research and devote their careers to the study of bone marrow diseases with the support of the AA&MDSIF researcher awards. Here’s what Dr. David Araten, a hematologist at Memorial Sloan-Kettering Cancer Center in New York, says about his 1996 award:

“The AA&MDSIF New Researcher Award that I received early in my training in hematology was immensely valuable to me at the time and has had extremely positive effects that are palpable to this day. The laboratory studies that I conducted with the support of the AA&MDSIF, demonstrated that the mutant cell populations that expand in patients with paroxysmal nocturnal hemoglobinuria (PNH) and aplastic anemia are actually present even in normal individuals—but in very small numbers. This work has also served as a foundation for my studies on the significance of abnormal morphologic features and abnormal chromosomes in the marrow of patients with PNH and also on the long term outcome of patients with aplastic anemia who have small PNH clones. These studies inform our understanding of the relationship between these 3 disorders, and it is extremely gratifying to answer my patients’ specific questions in part by explaining to them that this work supported by the AA&MDSIF.”

Families can participate directly in funding the research of dedicated doctors like Dr. Araten by raising money to fund a research study, which can be named in honor of their family or a loved one (see stories in previous newsletters). All donations are tax-deductible and 100% of all money donated goes directly to medical research — not one penny is taken out for any type of administrative expenses. A named Research Fund requires $30,000 a year for two years, totaling $60,000. A family can chose to fund either one year, or the full two years of a study, whichever their budget allows. It may seem like a challenging goal for a family to raise $30,000 or more, but there is no time limit on collecting the funds for a research study.

- **New Researcher Awards** — For new investigators conducting research in bone marrow failure diseases.
- **Established Researcher Awards** — For investigators with established track records conducting research in bone marrow failure diseases.
- **Bursary Awards** — For salaries of additional doctors and staff in laboratories focused on bone marrow failure diseases, with published records of high-quality basic or clinical research.
- **Specific Doctor Awards** — For a specific clinical researcher (doctor) with published records of clinical research.

Families and researchers who want to find out more about these opportunities should contact Marilyn Baker at (800) 747-2820 or baker@aamds.org.
ATTENTION MEDICAL RESEARCHERS...
The AA&MDSIF is now accepting applications for one New Researcher Award, and one Established Research Award. We are interested in funding medical research studies relating to the treatment of bone marrow failure diseases, specifically aplastic anemia and myelodysplastic syndromes. Application forms may be obtained by calling our office or can be downloaded from our website.

CONGRATULATIONS TO YAHN FAMILY...
Our congratulations and gratitude to Joanne & Don Yahn of Churchville, New York for once again getting friends and neighbors to join together in 2003 and raise $25,000 for the Tory Yahn Research Study.

EBULLETIN...
If you would like to receive our monthly bulletin via email, register at www.aamds.org under “Newsletters.”

GOOD WEBSITE...
www.uhftips.org  The United Health Foundation offers valuable tips on health management.

IN SEARCH OF...
We are in search of MDS patients who have been treated with Aza or Revlid and are interested in sharing their treatment experiences with others. Please contact Monica for more information.

I’M SORRY MAMA...
We apologize to Alice Braim, Louise Wessling’s mama, for spelling her name wrong in our end-of-year-thanks. Thank you Alice for your support!

COMMITTEE FOR INDIA...
We have created a committee dedicated to improving health care response and treatment options in India. If you would like to share different ideas on how to improve response to bone marrow failure patients and their families and generate increased awareness about aplastic anemia, MDS and PNH in India, contact Monica Grover at grover@aamds.org.

FROM THE DIRECTOR...

“Too often people who are ill lose touch with the things that bring them joy. Pain and limitation take over and they begin to see themselves as their illness.”

- Ann Steiner, Ph.D.
San Francisco Patient Conference

One of the costs of living is illness. None of us can escape the inevitable experience of being sick. Most of the time we cope easily, taking a few days off to rest and recuperate. But when chronic illness strikes, very different coping skills are required.

Although anger, outrage, and frustration are understandable reactions to serious illness, we sometimes forget that good health is a blessing and not a right. Even though we are told 90 million Americans suffer from chronic diseases, we still can’t believe it is happening to us. We ask, “Why me?” “Why now?” “Why this disease?” There are no easy answers. Our options are to either spend our energies obsessing over our disease, or to learn how to live our lives joyfully along with our illness.

Learning how to live with illness, or learning how to be a caregiver, can be a complicated process. While doctors battle to heal the physical body, patients and caregivers battle for their emotional health. As one patient told me, “The hardest part of being sick isn’t getting out of bed in the morning, it’s wanting to get out of bed at all.” Mood swings, chaotic behavior, panicked decisions...all are normal responses when trying to manage a life changing illness. The huge mental adjustments needed to cope can be learned with self-help books, counseling, spiritual assistance, and the support of loving family and friends. Learning is hard for some, easier for others. But regardless of the learning curve, all of us possess hidden reserves of strength and fortitude that emerge only when we are ill.

We must train ourselves to see, to be content with, and to celebrate the smallest joys that occur in our daily lives. While it can be hard to enjoy a candle when we’re used to watching fireworks, having an illness also gives us the opportunity to see and feel things we weren’t able to before. In the same way that a blind or deaf person comes to rely more heavily on their other senses, a patient or family living with chronic illness can often appreciate other parts of their lives more fully. And, hopefully, they will see joy in their world — not just their illness.

As we strive to provide you with information about your disease and treatment options, we also strive to assist you with your emotional needs. Please call us and let us know how we can help.

— Marilyn Baker, M.S.
Executive Director & Editor
WINDSURFING FOR 84-YEAR-OLD PATIENT

Joseph Miko’s 82nd birthday was just like any other day for him…first he spent 1 ½ hours lifting weights and riding the stationary bike, then he walked down to the ocean and went windsurfing, and later he ended his day with a rousing game of table tennis. Just a normal day for this extraordinary man!

Joseph was diagnosed with MDS two years ago. “First I was scared,” he remembers. “When the doctor told me I was absolutely shocked because I had spent my entire life as a healthy athlete. I went home and I gave myself a few days to get used to the idea. After the initial shock, and a couple of sleepless nights, I started gathering my thoughts, and made friends with the situation. Then I put my affairs in order and made sure my wife was taken care of. This gave me the peace I needed to live my life with a disease.”

According to Joseph, an athletic lifestyle is the secret to his current good health. He admits that some mornings he wakes up tired and tries to think of reasons not to exercise, but he forces himself to get moving. “I do different exercises every day for 1 ½ hours. Whether I feel like it or not, I make myself workout so I can stay strong enough to fight this disease. I am grateful to the AA&MDSIF for providing a means for patients to talk together. In sharing experiences with each other, we may be able to expand our knowledge. In circulating my information among people affected with this same disease, we may learn something from each other.”

HORSEBACK RIDING FOR 77-YEAR-OLD PATIENT

Vincent Rogers, “Vin”, recently bought himself a new horse! Vin has been an avid horse rider since he retired at age 70. Seeing him “Show Jump” his horse today you wouldn’t guess that he was thrown off balance in 1999 by aplastic anemia. “I had never heard of this disease and was devastated. I immediately called the AA&MDSIF, who reassured me that treatment was available, gave me the names of medical experts, and put me in touch with other patients who had successfully gone through treatment. The information I got from the AA&MDSIF gave me hope and encouraged me to pursue treatment. I have always been a spiritual person and that helped me to cope with my illness.”

Vin now considers himself cured by ATG treatment. So cured that at age 77 he plays tennis five times a week, rides horses three times a week, and gives thanks each a day for his good health.

“Sometimes we human beings need a jolt to remind us of how precious life is. All my life I have taken good care of myself – no smoking, no drinking, good diet, good exercise – so being sick was a shock to me. Now that I am cured, I appreciate every minute, of every day of this good life that I now have.” If you want to talk with this inspiring man, call him in Connecticut (860) 429-6676.
IT ALL STARTS WITH TELLING YOURSELF, I WANT TO HELP...

Phil Lewis recently ran the San Diego Rock and Roll Marathon in support of his friend Carolyn Shaw Glasow, who suffered from aplastic anemia, but is now in full remission. Phil raised thousands of dollars for the Carolyn Shaw Glasow Research Fund through AA&MDSIF. “Running for a good cause makes all the difference in the world. I want people to be aware of certain problems that others face. Carolyn is a good friend of mine and I wanted to help in any way possible.” At mile 24, Phil pulled his groin, hobbled the last 3 miles and amazingly finished the race in 4 hours and 20 minutes. Although injured during the race, he had the strength and perseverance to complete his first ever marathon.

After completing the race, Phil felt physically terrible and emotionally proud. How did he do it? “The main reason I was able to finish the race even with my groin injury is because I wanted to do it for Carolyn. My brother, Chris, kept me company as I finished the last few miles, which helped out immensely. Also, I just never considered the option of quitting. I probably got that from my Mom and Dad, who have been awesome role models for me. I knew a lot of people were counting on me to finish the marathon, so I didn’t give myself the choice of quitting.” He decided that he needed to train harder for the marathon again this year to help his friend Justin who is battling Lou Gehrig’s disease. “I see people fighting personal battles, some of which are out of their hands, and I want to help. It’s tough to see people you care about face difficulties in life. I think it is very important to raise awareness for certain issues. It tends to be easier sometimes to look the other way. Helping out really shows that people do care.” Carolyn Shaw Glasow, an aplastic anemia fighter is lucky to have a friend like Phil, a good-hearted human being with a dedication to helping others and an admirable loyalty in his friendships. Thank you, Phil, for being an inspiration to us all.

Please consider supporting Phil’s fundraising efforts through the AA&MDSIF.

THROUGH HYDE PARK & THE VILLAGES OF FRANCE...

Mathew Colliton, a young man who decided to participate in triathlon after triathlon in memory of his beloved friend, Katrin, tells his story... “The three day triathlon was one of the most incredible events that I have ever participated in,” Mathew said. He arrived in England on a Thursday afternoon, and stayed with a Dr. Goodman, who has hosted the London-Paris Triathlon for over twenty years. Still recovering from a bout of jetlag, Mathew began the race the next morning with a swim and run around Hyde Park. The race was segmented and one's placement in each event determined the overall victor. “I was very lucky to be placed on a wonderful team, Team Harris,” Mathew said. Mathew placed well in the swim and run and later took a train to France for the continuation of the race. “All the travel was catching up to me, but I was extremely motivated to do well for my friend Katrin who passed away in March of 2002.” On Saturday morning Mathew rose early to start his 25-mile bike ride through the villages of France. Mathew won the bike portion of the race. Later that evening during the awards ceremony after the triathlon, Mathew found out that he won the entire event.

The next day, Mathew headed back to London, and then went back to the US to get ready for another triathlon, Ironman, in Lake Placid. In reflecting on his experience in London and Paris, Mathew said, “It was a once in a lifetime event. Knowing that I was able to raise money for Katrin and share her life with others made the event unforgettable.” The world is a better place having such a dedicated friend as Mathew running to find a cure.

Please consider supporting Mathew’s fundraising efforts through the AA&MDSIF.
RECENT MEDICAL LITERATURE

Listed below are a few recently published journal articles indexed in the National Library of Medicine database MEDLINE: www.pubmed.gov. To obtain complete articles, contact your public or hospital library. These articles are listed for general information purposes only.

APLASTIC ANEMIA


MDS


PNH

Our Sincere Gratitude to the Herman Goldman Foundation of New York City  
for sponsoring this newsletter.
Their generous donation has made it possible 
for us to distribute this newsletter to thousands of patients and their families.

~

2004 ANNUAL PATIENT CONFERENCE!  
New and Improved Patient Friendly Presentations!

This year we will be changing the format of our doctors' presentations as to allow patients the ability to determine the topics of discussion. We expect approximately 300 patients and their families to share information, make friends, and learn the latest in research and treatment options. Located at the Holiday Inn at BWI airport, the hotel is just minutes away from Washington, Baltimore, and Annapolis – plan your sightseeing early!

And thanks once again to Pharmion Corporation, registration is FREE to the first 200 people who register!

*Registration Forms are enclosed in this newsletter, posted on our website,  
and available by calling the AA&MDSIF.*

REGISTER EARLY TO BE AMONG THE FIRST 200!

Aplastic Anemia & MDS  
International Foundation, Inc.  
P.O. Box 613  
Annapolis, Maryland 21404-0613  
(800) 747-2820  fax (410) 867-0240  
help@aamds.org  www.aamds.org

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For more information, please call the AA&MDSIF at:
800.747.2820 or 410.867.0242 or help@aamds.org

Know Where Your Money Is Going...
The American Institute of Philanthropy has determined that the reasonable industry standard for administrative and fundraising expenses is a maximum of 40%. The AA&MDSIF is proud to spend only 8%. Please compare our performance with other organizations when making your annual charitable contribution.